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ORIGINAL PAPER

Physician Mistrust, Medical System Mistrust, and Perceived Discrimination: Associations with HIV Care Engagement and Viral Load

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Abstract

Medical mistrust is an important risk factor for many health outcomes. For individuals with HIV and substance use comorbidities, mistrust may influence engagement with health care, and affect overall health and transmission risk. Medical mistrust can be measured by an individual's mistrust of his/her physician, or mistrust of the medical system. This study examined both types of mistrust among 801 substance-using individuals with uncontrolled HIV infection. The aims were to determine how physician mistrust, medical system mistrust, and discrimination experiences were associated with engagement in HIV primary care. Findings indicated higher levels of physician mistrust, but not medical system mistrust, were associated with a longer time since the last visit to an HIV provider. Longer time since seeing an HIV care provider was associated with higher viral load. This study refines our understanding of the relationship between mistrust and HIV care engagement for a large, diverse sample of substance-using individuals.

Keywords Medical mistrust · HIV · Discrimination · Health care engagement

Introduction

Linking individuals with HIV to care, and helping them to stay engaged, are core components of the National HIV/AIDS Strategy, which has set the goals of linking 85% of newly diagnosed individuals to HIV care (visit with an HIV health care provider) within 1 month of diagnosis and successfully maintaining that engagement (receiving at least one CD4 or viral load assessment per year) and 90% of individuals with known HIV infection in medical care [1]. However, only an estimated 77% of newly diagnosed individuals are linked to medical care within 1 month of diagnosis and only 49% of individuals living with HIV are optimally engaged in medical care [2]. Effective management and treatment of HIV is key to sustaining virologic suppression, improving overall health and quality of life, and preventing transmission to uninfected individuals [3–7]. Furthermore, the recent U = U (Undetectable = Untransmittable) campaign highlights research showing that individuals who maintain undetectable viral loads are not at risk of sexually transmitting HIV to an uninfected partner [8–10].

Clinical management among substance using PLWH (Persons Living with HIV) can be challenging because of medical and psychiatric comorbidities, involvement in the

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criminal justice system, structural barriers such as homelessness and food insecurity, and multiple forms of stigma associated with HIV status and drug use [11–13]. Drug use has been shown to be associated with lower probabilities of establishing HIV care following diagnosis [14], lower engagement across the HIV continuum of care [15, 16], and poorer health care use [17]. Further, studies have shown that active drug users with HIV are less likely to receive any HIV care [18, 19], and have poorer engagement with care [20–22]. On the other hand, studies have shown that drug users newly diagnosed with HIV who participated in substance use treatment (compared to those who did not participate in substance use treatment) have faster entry into HIV care [23]. While there is some research indicating that injection drug users with high physician mistrust tend to have lower levels of health care utilization, [24, 25], research targeting physician or medical system mistrust in this unique subgroup remains sparse.

Trust is an important component of effective health care. Historical examples of unethical medical experimentation, such as the U.S. Public Health Service Tuskegee Syphilis Study on Untreated Syphilis in the Negro Male [26], are only part of the complex context from which medical mistrust developed among marginalized individuals in this country. This context includes social inequalities, economic inequalities and extensive experiences of discrimination [27–29]. Medical mistrust is a potentially modifiable risk factor for sub-optimal engagement with health care among persons living with HIV (PLWH) and a potential mechanism for viral load management. Medical mistrust is operationalized in a variety of ways [30]. The present work examines two distinct facets: mistrust in one's own *physician* and mistrust in the broader health care *system*. Sources of physician mistrust may include specific, negative interactions with physicians or on-going, poor patient-physician relationships [31]. Physician mistrust is associated with poor adherence to antiretroviral therapy (ART), intensified psychological distress associated with treatment for PLWH, and can reduce PLWH's beliefs in treatment benefits [32–36]. In a study of injection drug users with HIV conducted in four U.S. cities, physician mistrust was associated with poorer health care use (fewer than two outpatient visits in the 6 months before the study interview) or using the emergency department for usual care [37]. Holtzman et al. [38] found poor relationships with HIV care providers to be a barrier to long-term engagement in care, defined as two or more visits with a primary HIV care provider within a 12-month period, among a predominantly non-white sample of PLWH. Another source of mistrust, mistrust in the health care *system,* may include beliefs that hospitals or clinics deceive or mislead patients, cover up mistakes when made, engage in harmful practices toward individuals without their knowledge, treat subgroups of patients better based on race or socio-economic status (race- or class-based medical mistrust), or generally fail to work in the best interests of the patient [39]. In studies of the general population, there is some evidence that higher levels of medical system mistrust are associated with underutilization of health care [40].

Discrimination experiences and stigma can be difficult to untangle from feelings of medical mistrust. There is some evidence that discrimination and medical system mistrust may distinctly affect the use of HIV health care, but the findings are inconsistent. For example, in one study of Black PLWH, medical system mistrust was associated with sub-optimal long-term medication adherence; however, racism-related mistrust was not associated with medication adherence [41]. Yet in another study of Black PLWH, race-based medical mistrust was negatively associated with medication adherence, but there were no associations between general medical mistrust and medication adherence [42]. Recent findings suggest the association between discrimination and HIV medication adherence may be mediated by medical system mistrust [43]. With respect to service use, there is evidence that perceived stigma (due to sexual orientation and/or race) from health care providers is associated with longer elapsed time since the individual's last appointment with an HIV provider for Black men who have sex with men [MSM; 44].

Few studies distinctly examine medical system mistrust and physician mistrust, particularly among PLWH. Cunningham et al. [45] reported high levels of medical system mistrust among Black and Hispanic women with HIV in New York even though most participants reported low levels of mistrust in their own physicians. By contrast, among a sample of predominantly Black PLWH in Mississippi, Krause and May [46] reported lower levels of mistrust in the health care system compared to mistrust in the quality of care and privacy protections provided by their physicians. We found only two studies examining the distinct associations of these two components of health care mistrust with HIV outcomes, including health care utilization. Eaton et al. [44] reported on associations between both medical system mistrust and physician mistrust and time since last physician visit among Black MSM. They found system mistrust was associated with poorer health care utilization among uninfected Black MSM (but not PLWH), but no associations between physician mistrust and health care utilization. Graham et al. [47] reported that baseline trust in physician, but not trust in the health care system, was associated with long-term engagement in HIV care, prospectively measured as seeing a physician in at least 3 of the 4 quarter-years in the year following diagnosis; and neither physician trust nor trust in the health care system were associated with linkage to HIV care. Taken together, these studies suggest that feelings of mistrust toward the health care delivery system are distinct from feelings of mistrust toward an individual's physician and may influence HIV health care utilization differently.

This study is a secondary analysis of baseline data from Project HOPE, a randomized controlled trial sponsored by the National Drug Abuse Treatment Clinical Trials Network. The goal of this analysis was to examine how physician mistrust, medical system mistrust, and experiences of discrimination are related to engagement in HIV primary care among a diverse sample of substance-using PLWH with uncontrolled HIV infection. A secondary goal was to examine whether there is an indirect effect of mistrust and/or discrimination on HIV viral load through engagement in HIV primary care.

Methods

Participants

Participants from this study come from Project Hope, a randomized controlled intervention trial targeting viral suppression among individuals with HIV [48]. The current research utilized baseline data from this study and included a total of 801 HIV-infected inpatients recruited from 11 hospitals across the United States between July 2012 and January 2014. Sites were hospitals with at least 200 unduplicated HIV-infected inpatients per year in cities with high prevalence of substance use among HIV-infected patients in Boston, MA, New York, NY, Philadelphia and Pittsburgh, PA, Baltimore, MD, Chicago, IL, Atlanta, GA, Miami, FL, Birmingham, AL, Dallas, TX, and Los Angeles, CA. The protocol was reviewed and approved by the institutional review boards at all sites.

Participants were eligible if they: (1) were HIV-infected inpatients at study sites, (2) were at least 18 years old, (3) signed a medical record release, (4) reported living near the study site and able to return for follow-up visits, (5) completed the baseline assessment and blood draw, (6) were able to communicate with project staff in English, (7) were willing and able to provide locator information, (8) had sufficient functional status as measured by a Karnofsky Performance Scale Index score of ≥ 60, (9) reported any opioid, stimulant, and/or heavy alcohol use within the past 12 months, and (10) met any of three HIV-related criteria (AIDS-defining illness, CD4 cell count < 350 cells/μL and a viral load > 200 copies/mL within the past 6 months, or CD4 count ≤ 500 cells/μL and a viral load > 200 copies/mL within the past 12 months).

Procedures

After providing written informed consent, inpatients were screened for eligibility. Eligible individuals were consented for full participation in the trial and enrolled. Participants completed blood draws and a social/behavioral assessment at baseline. All measures were collected via computer-assisted personal interviews. Participants received up to $50 for completing the baseline visit. Further information about the trial can be found in Metsch et al. [48].

Measures

Engagement with HIV Primary Care and Viral Load

Participants were asked if they had ever received HIV primary care, defined as "a clinician or team of clinicians who you see in a clinic or office on a regular basis and who works with you to manage your HIV/AIDS medications, blood test results, T cell count and viral load." Those endorsing primary care ($n = 664$) were then asked "When was your last primary care visit?" and given response options of 0–3 months ago, 3–6 months ago, 6–12 months ago and more than 12 months ago. From these data, we estimated regression models for two outcomes. The first was a measure of whether an individual had ever seen an HIV primary care physician (yes = 0, no = 1) and the second was an ordinal variable indicating time since last visit (1 = 0–3 months, 2 = 3–6 months, 3 = 6–12 months, and 4 = 12 + months). The HIV-related outcome was HIV-1 plasma viral load (using log10 transformation to account for skew), taken at baseline.

Mistrust and Discrimination

Medical system mistrust was measured by a 12-item scale that measures the suspicion of mainstream health care professionals and systems and perceptions of the general medical treatment provided to an individual's racial or ethnic group [49]. The scale's authors report high internal consistency ($\alpha = 0.83$) and our findings were consistent ($\alpha = 0.85$). All participants were asked to rate their level of agreement (1 = strongly disagree, 5 = strongly agree) with statements about the experiences of people from their racial/ethnic group with the health care system in general, such as "Doctors and health care workers sometimes hide information from patients who belong to my ethnic group" and "Doctors and health care workers do not take the medical complaints of people of my ethnic group seriously." Items were scaled so that higher values indicated more medical system mistrust. To account for potential measurement error, the items were modeled as indicators of a latent variable for medical system mistrust.

Physician mistrust was also operationalized as a latent variable, indicated by three items selected based on conceptual criteria from the Physician–Patient Relationship measure [35]. Two items, "I can tell my health care provider anything" and "My health care provider cares as much as I do about my health" were rated on a 5-point scale (1 = strongly agree, 5 = strongly disagree), and one item, "All things considered, how much do you trust your health care provider" was rated on a 10-point scale ranging from "least trust possible" to "most trust possible." Items were scaled so that higher values indicated higher levels of physician mistrust. The internal consistency of the three observed items was adequate (α = 0.71). Physician mistrust was only assessed for participants who reported having a current HIV physician at baseline (n = 549).

Participants were asked to report on whether they had ever experienced discrimination in a health care setting as a result of their gender, race/ethnicity, sexual orientation, HIV-status, or drug use. Data were coded 1 for endorsement of any type of discrimination (including multiple endorsements) and 0 for no endorsement.

Covariates

Analyses controlled for age, gender, and race/ethnicity. Race/ethnicity was coded for mutual exclusivity so that participants were identified as either Black, Hispanic, or Caucasian (reference group). Participants were coded as homeless if they indicated they were homeless (e.g. living on the street, in a park, in a bus station) most of the time in the past 6 months. Heavy alcohol use was measured by the Alcohol Use Disorders Identification Test [AUDIT; 50] with a score > 7 indicative of harmful or hazardous drinking [51]. Drug use severity was measured by the Drug Abuse Screening Test (DAST) with a score > 6 indicative of a substantial problem level related to drug use [52].

Health literacy was assessed using a variation of the Brief Health Literacy Screening Tool [53]. This three-item measure asked participants to indicate on a 5-point scale how often they had someone help them read hospital materials (4 = never, 0 = always), how confident they felt completing medical forms by themselves (4 = extremely, 0 = not at all), and how often they experienced problems understanding written information about their medical condition (4 = never, 0 = always). The internal consistency of the three observed items was adequate (α = 0.73). To account for measurement error, these items were indicators on a latent variable with higher scores indicating higher health literacy.

Poor access to health care was assessed using the Access to Care Scale [54], a 6-item measure asking participants to rate their level of agreement (strongly disagree to strongly agree) with statements such as "If I need hospital care, I can get admitted without trouble" and "Places where I can get medical care are very conveniently located." Internal consistency for the observed items was adequate (α = 0.72). To account for potential measurement error, these items were indicators of a latent variable. Higher values on this scale were associated with worse perceived access to health care.

Analysis Plan

The analyses began with examinations of the latent variables for medical system mistrust, physician mistrust, poor access to care, and health literacy. We estimated a confirmatory factor analysis for each construct separately to assess model fit and standardized loadings. To assess model fit we used the Comparative Fit Index (CFI) and Root Mean Square Error of Approximation (RMSEA) with criteria of CFI > 0.95 or RMSEA < 0.06 to indicate adequate fit [55] and calculated omega model-based reliability [56]. We then estimated a structural equation model that regressed viral load on the two primary outcomes (ever/never had primary care, timing of last visit). This model also simultaneously regressed the two primary outcomes, using logit and cumulative logit link functions, respectively, on medical system mistrust, physician mistrust (for timing of last visit only), whether the participant experienced discrimination, and all covariates. The entire sample was included in all analyses (N = 801). Missing data were accounted for by full information maximum likelihood, which uses all available data for parameter estimation [57]. All analyses were performed using Mplus [58].

Results

Descriptive statistics of the study sample (n = 801) are presented in Table 1. Three-quarters of the sample was African American and 11% Hispanic. The majority of the sample was male (67%) and most had at least a high school education (60%). A quarter of the sample reported homelessness in the past 6 months. The median baseline CD4 count was 109 cells/µL and 66% of the participants had a baseline CD4 count below 200 cells/µL. The median baseline viral load was 56,658 copies/µL. The mean AUDIT score in this sample was 9.04 (SD = 9.54) and 43% of the sample had AUDIT scores > 7. The mean DAST score was 4.69 (SD = 2.93) in this sample, with 42% reporting a DAST score > 6. Of the entire sample, 66% had elevated values on the DAST, AUDIT, or both.

Seventeen percent of the sample had never seen an HIV primary care physician. Of those who had ever seen an HIV primary care physician, 53% reported their last visit was 0–3 months prior to baseline, 15% reported 3–6 months prior to baseline, 12% reported 6–12 months prior to baseline, and 20% reported more than a year ago.

Twenty-nine percent of participants indicated they experienced at least one type of discrimination in a health care setting, and 18% reported multiple discriminatory experiences. Of the total sample, 20% reported discrimination due to their HIV status, 15.5% due to drug use, 10% due to race, 8% due to sexual orientation, and 5% experienced gender discrimination. A higher proportion of Caucasian

Table 1 Sample statistics

	Frequency/N[a]	Mean (standard deviation) or percentage
Age	801	44.68 (9.99)
Male	540/801	67.4%
Race		
Black	618/797	77.5%
Hispanic	88/796	11.1%
Caucasian	152/797	19.1%
Homeless in the past 6 months	206/801	25.7%
High school education (or higher)	482/801	60.2%
AUDIT Score	797	9.04 (9.54)
DAST Score	799	4.69 (2.93)
Living in Southern U.S.	399/801	49.8%
Discrimination		
Any discrimination	232/801	29.0%
HIV discrimination	159/794	20.0%
Gender discrimination	42/795	5.3%
Sexual orientation discrimination	60/794	7.6%
Racial discrimination	81/791	10.2%
Drug use discrimination	123/793	15.5%
Last visit to HIV primary care provider		
Never	135/799	16.9%
> 12 months ago	128/636	20.1%
6–12 months ago	75/636	11.8%
3–6 months ago	92/636	14.5%
0–3 months ago	341/636	53.6%

[a] Indicates the sample size for which data were available

participants (40%) reported any kind of discrimination compared with Black (27%) participants ($\chi^2_{(1)} = 7.80$, $p < 0.01$). Compared to non-Caucasian participants, there were significantly higher proportions of Caucasian participants reporting discrimination due to sexual orientation (Caucasian = 15%; non-Caucasian = 6%; $\chi^2_{(1)} = 9.61$, $p = 0.002$) and drug use (Caucasian = 23%; non-Caucasian = 14%; $\chi^2_{(1)} = 5.40$, $p = 0.02$). Over one-third (35%) of Hispanic participants reported experiencing some form of discrimination in a health care setting.

The confirmatory factor analysis for medical system mistrust demonstrated good global fit (CFI = 0.96, RMSEA = 0.06) and good reliability (omega = 0.76). The latent variables for physician mistrust and health literacy were each comprised of three observed items, thus measures of global fit were not informative. For physician mistrust, the standardized loading for each item was above 0.69 and significant at $p < 0.001$. The physician mistrust latent variable demonstrated good reliability (omega = 0.79). The standardized loadings for health literacy were all above 0.67 and were statistically significant at $p < 0.001$. This latent variable also had good reliability (omega = 0.73). Access to care had adequate fit (CFI = 0.93, RMSEA = 0.10) and good reliability (omega = 0.77).

The structural equation model is show in Fig. 1 and the parameter estimates are in Table 2. The model explained approximately 12% of the variance in viral load (pseudo $R^2 = 0.12$, $p < 0.001$), 21% of the variance in having ever seen an HIV primary care provider (pseudo $R^2 = 0.21$, $p < 0.001$) and 11% of the variance in last visit with an HIV provider (pseudo $R^2 = 0.11$, $p < 0.001$) with good model fit (RMSEA = 0.033, 90% confidence interval: 0.03, 0.04).

Engagement: Never Had HIV Primary Care

Controlling for all covariates, poorer perceived access to health care (OR 1.82, 95% CI 1.40–2.38), homelessness (OR 1.47, 95% CI 1.01–2.13), and living in the Southern U.S. (OR 1.53, 95% CI 1.21–1.94) were associated with higher odds of never receiving HIV primary care. Older age (OR 0.99, 95% CI 0.98 to < 1.00) and higher drug use severity (OR 0.96, 95% CI 0.92 to < 1.00) were associated with lower odds of never receiving HIV primary care. Neither medical system mistrust nor any of the experiences of discrimination were associated with having never received HIV primary care.

Engagement: Last Visit to HIV Primary Care Provider

Controlling for the covariates, timing of the last physician visit was significantly associated with physician mistrust (OR 1.11, 95% CI 1.03–1.20), suggesting odds of a longer time elapsed since last physician visit increasing 1.11 times for each unit increase in physician mistrust. Among the covariates, higher levels of health literacy (OR 1.17, 95% CI 1.02–1.36), experiencing homelessness (OR 1.49, 95% CI 1.06–2.08), and living in the southern U.S. (OR 1.44, 95% CI 1.18–1.75) were associated with a longer elapsed time since the individual's last visit with an HIV provider.

Viral Load

Controlling for all covariates and the mistrust and discrimination measures, both longer time elapsed since seeing an HIV primary care provider ($b = 0.20$, $p < 0.01$) and having never received HIV primary care ($b = 0.17$, $p = 0.01$) were significantly and positively associated with viral load. The indirect effect of physician mistrust on viral load through timing of the last visit to HIV primary care was statistically significant ($b = 0.02$, $p = 0.02$) such that physician mistrust was associated with greater time elapsed since seeing a physician, and longer time since seeing a physician was associated with higher viral load.

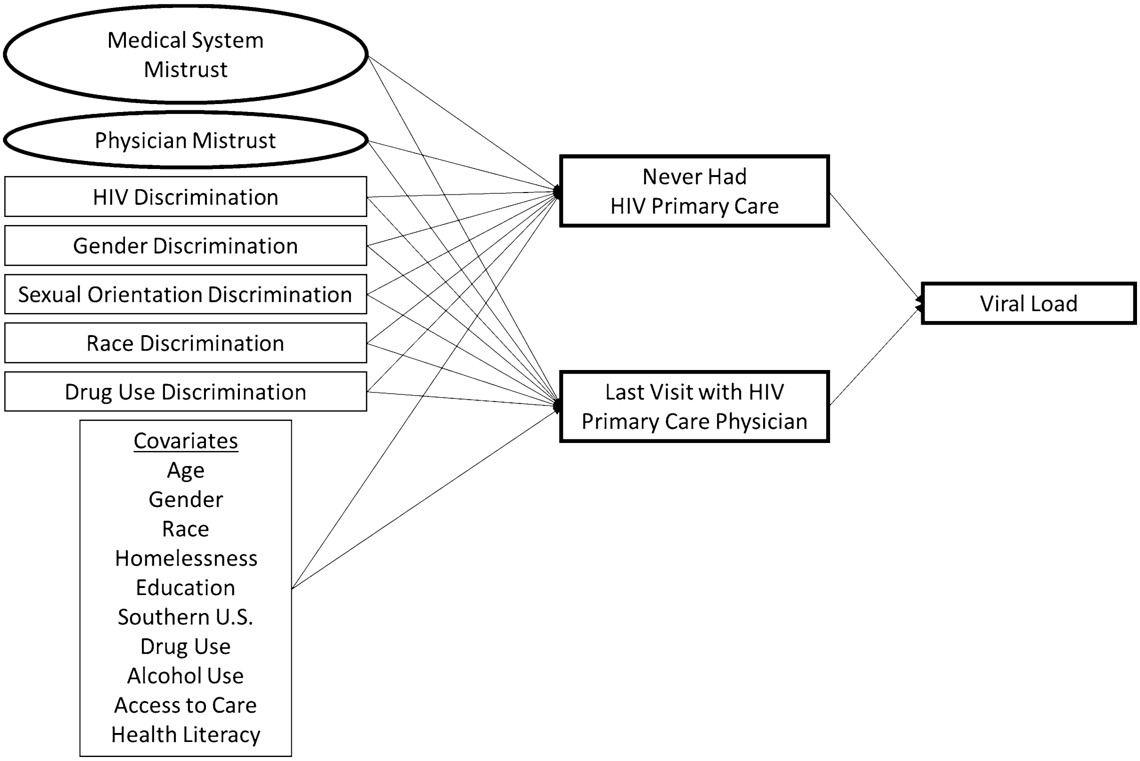

Fig. 1 Structural equation model regressing viral load on engagement with HIV primary care. Viral load was also regressed on all covariates (paths omitted from figure)

Discussion

The purpose of this secondary data analysis was to examine the association of physician mistrust, medical system mistrust, and experiences of health care discrimination with health care engagement in a unique sample of individuals with uncontrolled HIV disease and substance use comorbidities. The data reported here are from the largest study of substance-using PLWH with uncontrolled infection in the U.S. to date and provides an important lens through which to examine medical mistrust and the HIV care continuum. Notably, the majority of the sample was minority and male with low levels of education, significant homelessness, and HIV and substance use comorbidities.

Nearly a third of the sample reported some experience of discrimination in a health care setting and consistent with previous research, 1 in 5 participants reported their discrimination experience was due to their HIV status [59]. The difference in the proportion of Caucasians versus non-Caucasians in reporting experiences of discrimination was consistent with findings from a nationally representative sample of individuals with HIV in which Caucasian participants were more likely than non-Caucasians participants to report experiences of discrimination in a health care setting [59]. To better understand this finding, we conducted post hoc analyses stratified by geographic location (Southern U.S. vs. Northern U.S.). The race differences in the proportion of participants reporting any discriminatory experience was statistically significant in the South (Caucasian = 41%; non-Caucasian = 24%; $\chi^2_{(1)} = 6.40$, p = 0.01) but not the North (Caucasian = 39%; non-Caucasian = 30%; $\chi^2_{(1)} = 1.43$, p = 0.23). These patterns persist for discrimination specific to race, gender, drug use and sexual orientation. This is consistent with findings from a study of 366 women with HIV recruited from HIV clinics in Georgia and Alabama in which significantly higher rates of HIV discrimination were reported by Caucasian women compared to Black women [60]. The authors propose that African American women may have had lower likelihoods of reporting the discriminatory experiences due to internalization of pervasive negative views of their culture. By regional contrast, among individuals with HIV recruited in the Midwest U.S., no race-based differences were detected in the experiences of discrimination due to HIV or socioeconomic status [61]. Mayrl and Saperstein [62] suggest that stronger racial identities among Caucasians in the South may explain elevated reporting of racial discrimination among Caucasians in the Southern U.S. There is also some evidence to suggest that individuals in a setting where they are a racial minority are more likely to report discrimination [63].

Table 2 Structural Equation Model results with adjusted Odds Ratio (aOR) and unstandardized regression coefficients (b)

	Never had HIV primary care[a]		Timing of last visit to HIV primary care[b]		Viral load	
	aOR	95% CI	aOR	95% CI	b	p-value
Age	**0.99***	**0.98 to < 1.00**	0.99	0.98–1.00	**−0.01***	**0.01**
Male	0.98	0.77–1.25	0.96	0.78–1.18	0.00	0.97
Black (vs. Caucasian)	1.19	0.84–1.68	1.06	0.80–1.41	0.00	< 1.00
Hispanic (vs. Caucasian)	1.01	0.63–1.62	0.96	0.65–1.42	0.24	0.17
Homelessness (vs. not)	**1.47***	**1.01–2.13**	**1.49***	**1.06–2.08**	0.37	0.06
High School Education (vs. less than H.S.)	0.99	0.79–1.25	1.04	0.85–1.28	0.02	0.82
AUDIT Score	1.00	0.98–1.01	0.99	0.98–1.00	0.00	0.42
DAST Score	**0.96***	**0.92 to < 1.00**	1.00	0.97–1.04	−0.02	0.28
Southern U.S. (vs. Northern)	**1.53***	**1.21–1.94**	**1.44***	**1.18–1.75**	0.13	0.18
HIV discrimination	0.75	0.50–1.14	0.90	0.67–1.20	−0.04	0.78
Gender discrimination	0.61	0.29–1.27	1.18	0.68–2.05	0.27	0.27
Sexual orientation discrimination	1.37	0.79–2.39	0.80	0.50–1.27	0.03	0.87
Racial discrimination	0.63	0.33–1.18	1.06	0.70–1.58	0.11	0.56
Drug use discrimination	1.13	0.74–1.71	1.22	0.87–1.70	−0.14	0.29
Health literacy	1.11	0.96–1.27	**1.17***	**1.02–1.36**	−0.05	0.50
Poor access to care	**1.82***	**1.40–2.38**	1.16	0.96–1.40	0.03	0.84
Medical system mistrust	1.03	0.87–1.22	1.01	0.86–1.19	0.04	0.62
Physician mistrust	–	–	**1.11***	**1.03–1.20**	0.00	0.93
Never had HIV primary care	–	–	–	–	**0.17**	**0.01**
Last HIV primary care visit	–	–	–	–	**0.20**	**< 0.01**
R^2	0.21 $p<0.001$		0.11 $p<0.001$		0.12 $p<0.001$	

[a] This outcome variable was coded 1 if the participant had never experienced HIV primary care, and 0 if the participant had experienced HIV primary care

[b] This outcome variable had four ordinal responses: 0–3 months ago, 3–6 months ago, 6–12 months ago and more than 12 months ago

*Statistically significant at $\alpha=0.05$

Given the study sites in the Southern U.S. included major cities in which Caucasians represent a racial minority, this may be contributing to the differences in the rates of reporting discrimination experiences in this sample.

Individuals reporting higher levels of physician mistrust had higher odds of a longer time elapsed since seeing an HIV primary care provider. This is consistent with the findings of Graham et al. [47] who reported baseline physician trust was positively associated with prospectively-measured engagement in HIV care. These results contrast those of Eaton et al. [44] who found no association between either medical mistrust or physician mistrust and time since last examination among a smaller sample Black MSM recruited from a local festival. The considerable differences in the samples may account for the disparity. Participants in the current study were experiencing multiple comorbidities, poor health, and high rates of sub-optimal engagement in health care. For these individuals, the relationship with an HIV provider may play a more critical role for continued engagement with care.

Participants who were younger, homeless, who lived in the Southern U.S. or who reported poorer access to care had higher odds of never engaging with HIV primary care. Individuals with more severe drug use problems had higher odds of engaging with HIV primary care. Possible explanations could be that individuals engaged in heavy drug use are more connected to the health care system as a result of more severe health problems or as a result of engagement with previous drug use disorder treatment that may have connected them with HIV care. Indeed, other studies have reported that PLWH who had been in drug treatment in the past year experienced earlier entry into HIV care [23]. Among those who did engage with HIV primary care, a longer time had elapsed since the last visit for those who recently experienced homelessness, lived in the South, or had higher health literacy.

Not surprisingly, never having HIV primary care and, for those who had HIV primary care, a longer time since last visit with an HIV primary care provider were associated with higher viral loads. This is consistent with previous literature linking suboptimal engagement in care to poor virologic outcomes [64, 65]. Combined with the previous findings showing an association of physician mistrust with longer elapsed time since seeing an HIV provider, there is evidence for an indirect effect of physician mistrust on viral load through timing of the last visit to HIV primary care. This suggests that one possible mechanism through which physician mistrust might influence viral load is through fewer visits with an HIV physician. Thus, PLWH who have high levels of physician mistrust are less likely to participate in follow-up care that is critical to viral load management, resulting in poorer viral load outcomes. These findings suggest that efforts to restore and maintain physician trust may be a promising approach to improving HIV health care utilization and ultimately, reducing viral load among substance-using PLWH. Given the high proportions of individuals reporting experiences of health care discrimination due to their HIV status, continuing efforts to identify and address sources of discrimination and stigma may be a step toward restoring trust with health care providers. One qualitative study identified respect and partnership as key components of trusting patient-provider relationships [66].

Although the sample was sub-optimally engaged with the health care system, reported levels of physician mistrust were low. Cunningham et al. [45] reported findings of higher trust in physicians among HIV-positive minority women when compared with minority women who did not have HIV and offered possible explanations that included (1) unique abilities for developing rapport among physicians trained to work with HIV-affected populations, (2) requirements of a more trust-based physician–patient relationship due to the nature of HIV disease, and (3) a possibility that individuals with HIV are more connected to the health care system by virtue of their chronic health needs. These HIV providers might be more attuned to the needs of infected individuals and marginalized populations and may be more comfortable with the physician–patient conversations requiring a candidness about sensitive issues such as drug use and sexual behaviors.

This work has some notable limitations. All measures were taken from baseline, resulting in cross-sectional analysis and an inability to make causal statements about the influence of any of the variables. All measures were also self-report, and though the use of latent variables did model measurement error, the possibility for biased reporting is still present. Participants self-reports of visits with an HIV primary care provider were significantly correlated with medical record extractions (Spearman $r = 0.82$). The study did not collect information on some covariates that have demonstrated importance in other studies of medical mistrust (e.g., racial/ethnic concordance between physician and patient [67]. As noted earlier, physician mistrust was only measured among the portion of the sample that had a current HIV physician. Analytically, ordinal logistic regression carries a proportional odds assumption which assumes that the coefficients describing the relationship between outcome categories are the same between pairs of contiguous cutpoints. For example, the coefficient for 0–3 months versus 3–12 months is assumed to be the same as the coefficient for 0–6 months versus 6–12 months. Engagement was measured as the previous visit with an HIV physician, rather than prospectively. The measure of group-based medical mistrust does not necessarily capture mistrust based on sexual orientation, gender, substance use, HIV status or other characteristics. Finally, the study sample is not representative of the broader population of individuals with HIV, thus limiting the generalizability of these findings.

This study furthers our understanding of the complexities of medical mistrust and discrimination as they relate to engagement in health care among substance-using individuals living with HIV. The findings are consistent with smaller recent studies demonstrating the importance of physician mistrust on health care engagement for a large, diverse sample of HIV-infected, substance-using individuals. The historical context from which medical mistrust has developed for marginalized populations in this country, as well as existing social, political and structural barriers to fostering trust in health care as discussed briefly in the introduction provide an important backdrop to this work.

Significant, further research is needed to identify effective approaches to restoring and maintaining trust in physicians and medical systems for everyone, but especially for marginalized and vulnerable populations. Murray and McCrone [68] examined trust in the primary care setting across a number of studies and found provider interpersonal skills such as emotional intelligence and provider communication had the strongest associations with patient trust. The studies in this review were predominantly cross-sectional, and only one was a randomized controlled trial. This suggests an enormous gap in our understanding of how interventions targeting communication between physicians, and perhaps health care systems, and patients might increase trust. There is recent empirical evidence that interventions can be effective at improving physicians' patient-centered communication skills [69], but links to the impact of these improvements on patient trust were not examined. For patients in primary care settings, health coaching is another promising approach to improving trust among low-income Hispanic individuals [70], suggesting that structural changes to how health care is delivered may be an effective approach at enhancing trust. Finally, at the patient-level, interventions that target enhancing patients' self-efficacy beliefs about effectively communicating with their health care providers may have the potential to increase patient trust through improvements in the patient-provider relationship [71]. Longitudinal studies of mistrust, and studies that test theoretical mechanisms through which improvements in trust might improve health care utilization among individuals with HIV are two important areas of future research.

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Compliance with Ethical Standards

Conflict of interest Dr. Schwartz provides consultation to Verily Life Sciences. All other authors declare that they have no conflicts of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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